Disaster Research Ethics: Developing Evidence Ethically

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Disaster Bioethics

http://disasterbioethics.eu

DCU

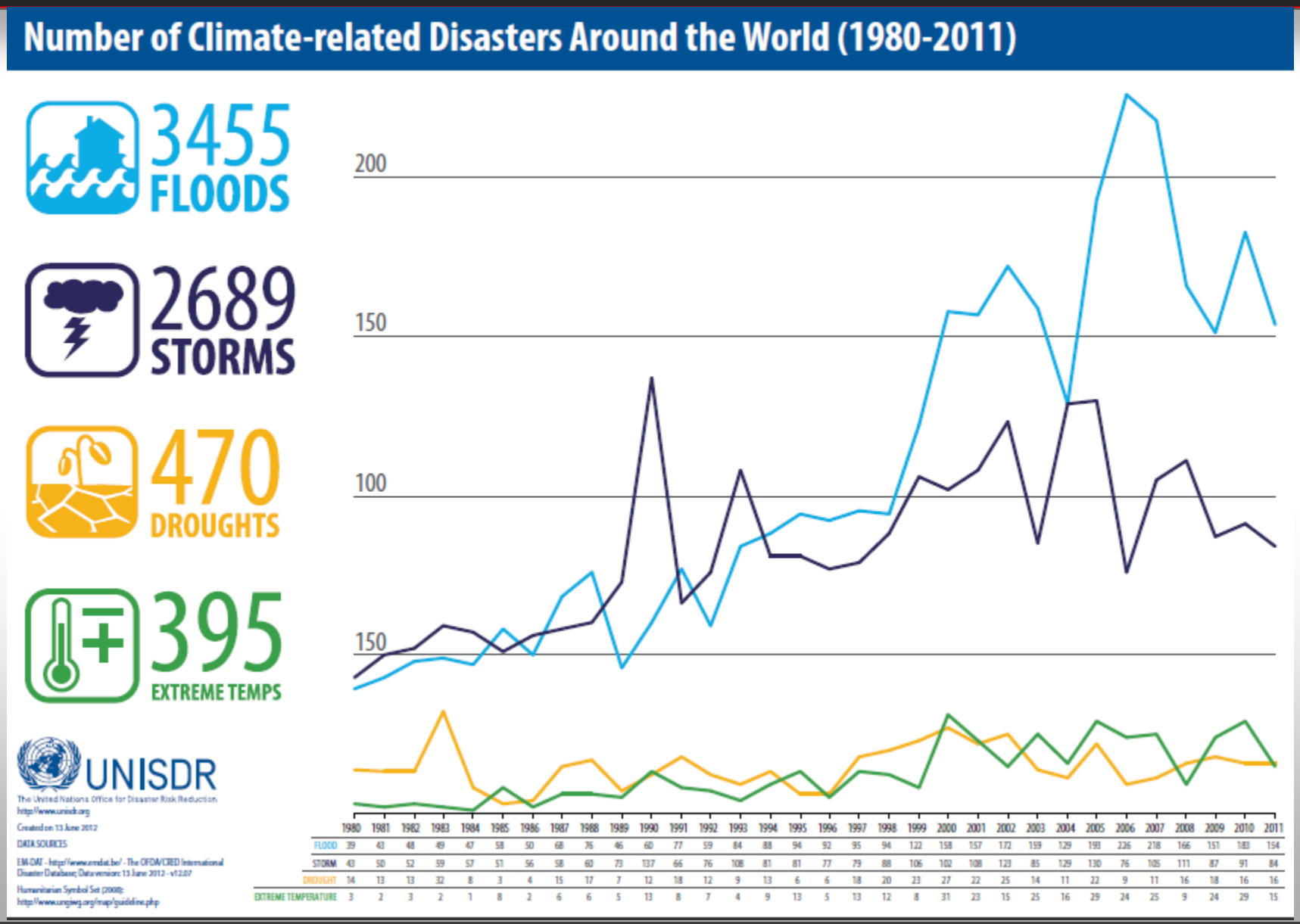
Definition

Disaster: ‘A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability and capacity, leading to one or more of the following: human, material, economic and environmental losses and impacts.’

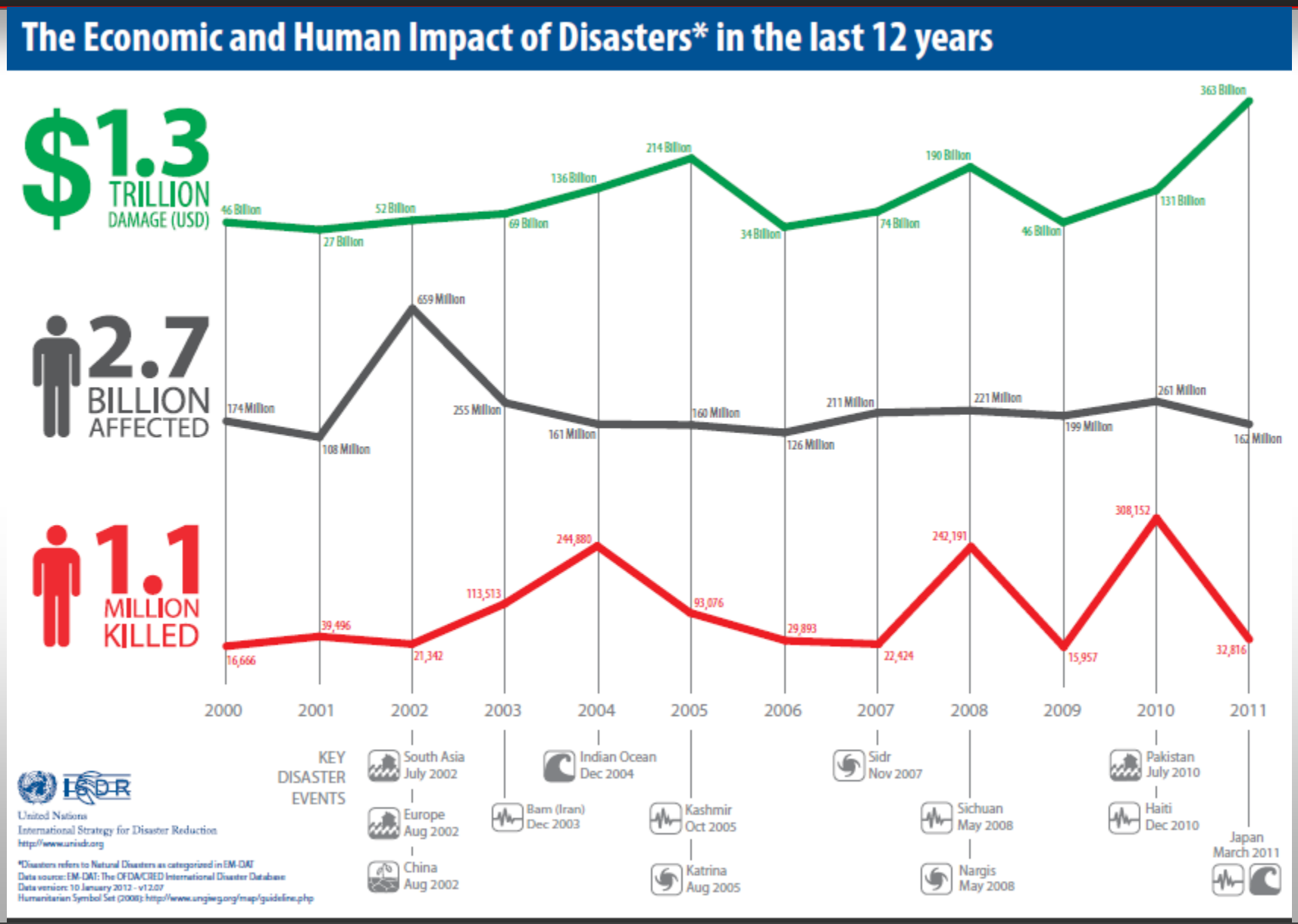
Effect may exceed local capacity requiring external assistance.

UN Office for Disaster Risk Reduction (UNISDR): https://www.unisdr.org/we/inform/terminology

Frequency


Number of Climate-related Disasters Around the World (1980-2011)
3455 FLOODS
2689 STORMS
470 DROUGHTS
395 EXTREME TEMPS
200
150
100
150
UNISDR
The United Nations Office for Disaster Risk Reduction
http://www.unisdr.org
Created on 13 June 2012
DATA SOURCES
EM-DAT - http://www.emdat.be/ - The OFDA/CRED International Disaster Database; Data version: 13 June 2012 - v12.07
Humanitarian Symbol Set (2008): http://www.unsgiwg.org/map/guideline.php
1980 1981 1982 1983 1984 1985 1986 1987 1988 1989 1990 1991 1992 1993 1994 1995 1996 1997 1998 1999 2000 2001 2002 2003 2004 2005 2006 2007 2008 2009 2010 2011
FLOOD 39 43 48 49 47 58 50 68 76 46 60 77 59 84 88 94 92 95 94 122 158 157 172 159 129 193 226 218 166 151 183 154
STORM 43 50 52 59 57 51 56 58 60 73 137 66 76 108 81 81 77 79 88 106 102 108 123 85 129 130 76 105 111 87 91 84
DROUGHT 14 13 13 32 8 3 4 15 17 7 12 18 12 9 13 6 6 18 20 23 27 22 25 14 11 22 9 11 16 18 16 16
EXTREME TEMPERATURE 3 2 3 2 1 8 2 6 6 5 13 8 7 4 9 13 5 13 12 8 31 23 15 25 16 29 24 25 9 24 29 15

Impact

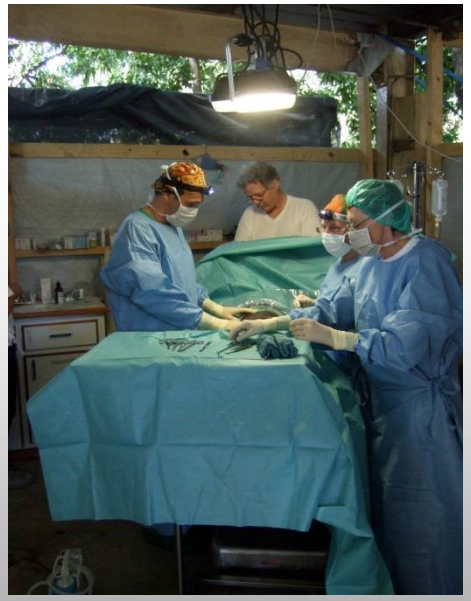

The Economic and Human Impact of Disasters* in the last 12 years
$1.3 TRILLION DAMAGE (USD)
2.7 BILLION AFFECTED
1.1 MILLION KILLED
46 Billion
27 Billion
52 Billion
69 Billion
136 Billion
214 Billion
34 Billion
74 Billion
190 Billion
46 Billion
131 Billion
363 Billion
174 Million
108 Million
659 Million
255 Million
161 Million
160 Million
126 Million
211 Million
221 Million
199 Million
261 Million
162 Million
16,666
39,496
21,342
113,513
244,880
93,076
29,893
22,424
242,191
15,957
308,152
32,816
2000
2001
2002
2003
2004
2005
2006
2007
2008
2009
2010
2011
KEY DISASTER EVENTS
South Asia July 2002
Europe Aug 2002
China Aug 2002
Bam (Iran) Dec 2003
Indian Ocean Dec 2004
Kashmir Oct 2005
Katrina Aug 2005
Sidr Nov 2007
Sichuan May 2008
Nargis May 2008
Pakistan July 2010
Haiti Dec 2010
Japan March 2011
United Nations
International Strategy for Disaster Reduction
http://www.unisdr.org
*Disasters refers to Natural Disasters as categorized in EM-DAT
Data source: EM-DAT: The OFDA/CRED International Disaster Database
Data version: 10 January 2012 - v12.07
Humanitarian Symbol Set (2008): http://www.ungiwg.org/map/guideline.php

Responding

- **“We don’t really know which interventions are most effective in reducing risk, saving lives and rebuilding livelihoods after crises**… At present, humanitarian decisions are often based on poor information… It is extremely difficult for practitioners to access information about good practice in order to improve their own effectiveness, because information is scattered and is not available in a consistent format” (DFID, p. 5)

http://www.alnap.org/resource/9823.aspx

- “much of the existing operational research related to emergencies and disasters lacks consistency, is of poor reliability and validity and is of limited use for establishing baselines, defining standards, making comparisons or tracking trends” (p. 46).
  - UNISDR. *Hyogo Framework for Action 2005-2015*, Mid-Term Review 2011.



Photographs courtesy of Johan Von Schreeb

- "The failure to generate and use evidence in policy and response makes humanitarian action less effective, less ethical and less accountable" (ALNAP, 2014, p. 5).

- It is "unethical to deliver interventions that are, at best not proven, are ineffective or, worse still, do actual harm" (DFID, 2012, p. 11).

http://www.alnap.org/resource/10441

- “Many practitioners consider research in disaster settings to be unethical. In addition to being perceived as taking away resources from humanitarian aid, there are concerns that research can be an imposition on those already suffering, and that it does not immediately help those being studied” (DFID, 2012, p. 11).

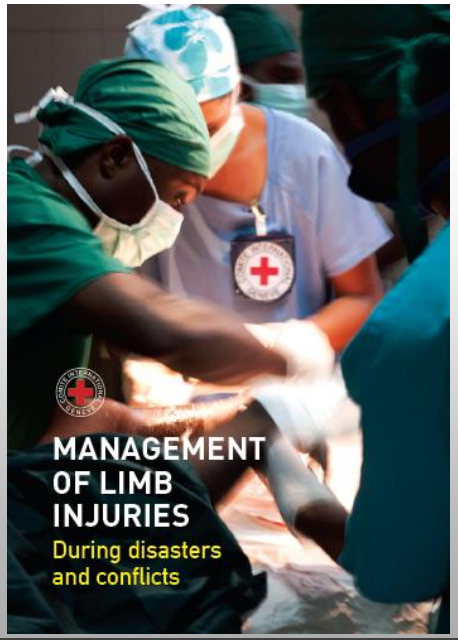
Photograph courtesy of Pretesh Kiran

Example: Surgery in Haiti (2010)

- Widely divergent amputation rates between surgical teams (from 1% to 45% of procedures conducted).
- Records often not kept.
- Allegations of “disaster tourism”.
- Led to retrospective studies, quantitative and qualitative.
- WHO minimum standards (2013), ICRC/WHO/AOF Manual (2016):

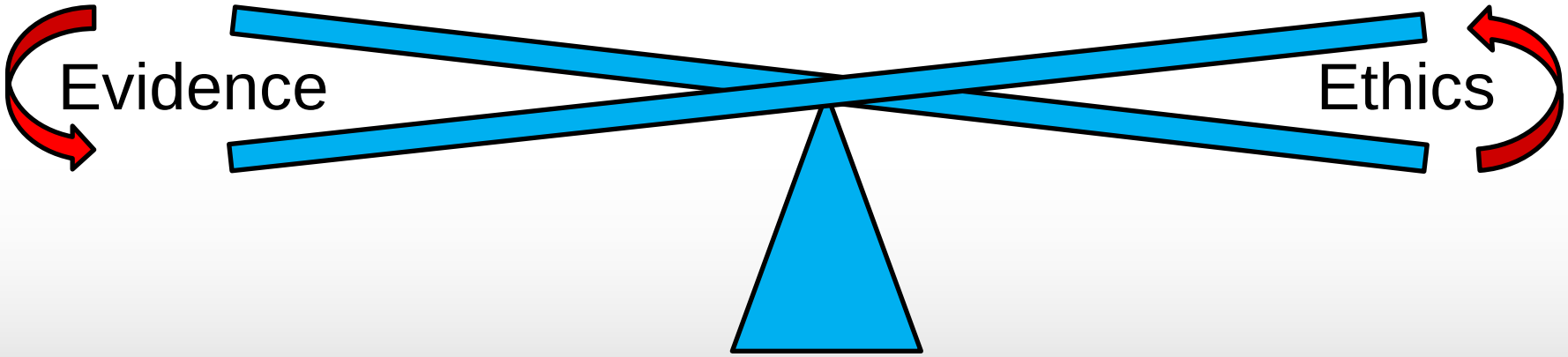
O’Mathúna DP, Von Schreeb J. *UNISDR Scientific and Technical Advisory Group Case Studies – 2015*. http://bit.ly/1z9NVgl

Photo: Johan Von Schreeb



https://icrc.aoeducation.org

Dual Imperative



Research Ethics Frameworks

- Council for International Organizations of Medical Sciences (CIOMS), *International Ethical Guidelines for Health-related Research Involving Humans*, Guideline 20: Research in Disasters and Disease Outbreaks (2016): http://www.cioms.ch/
- R2HC Ethical Framework (2014): http://www.elrha.org/R2HC
- Doctors Without Borders/Médecins Sans Frontières (MSF) Ethics Review Board (2013): http://fieldresearch.msf.org/msf/handle/10144/305288
- Working Group on Disaster Research and Ethics (2011): https://globalhealthtrials.tghn.org/articles/draft-statementguidelines-disaster-research/

What sort of research?

- Medical interventions: randomised controlled trials (RCTs)
- “However, researchers, sponsors, research ethics committees and others must explore alternative trial designs [in disasters] that may increase trial efficiency and access to promising experimental interventions while still maintaining scientific validity. The methodological and ethical merits of alternative trial designs must be carefully assessed before these designs are used” (CIOMS Guideline 20 Commentary, 2016).
- Cluster randomised controlled trials
- Time series studies
- Outcome measurement
- Qualitative interviews
- Surveys
- Mixed methods studies

Benchmarks of Ethical Research

1. Collaborative partnership
2. Social value
3. Scientific validity
4. Fair selection of study population
5. Favorable risk-benefit ratio
6. Independent review
7. Informed consent
8. Respect for recruited participants and study communities

Emanuel EJ, Wendler D, & Grady C. What makes clinical research ethical in developing countries? The benchmarks of ethical research. *Journal of Infectious Diseases* 2004;189(5):930-937.

1. Collaborative Partnership

- Engage with local communities at all stages of research, from design to implementation to dissemination. Ethics does not begin with the research ethics (IRB) approval process.
- "The most appropriate decisions are likely to be made when ethical issues are thought about prior to starting research. Researchers are most likely to 'do harm' when they do not anticipate likely ethical challenges" (p. 13).
  - Goodhand J. Research in conflict zones: Ethics and accountability. *Forced Migration Review* 2000;8:12-15
- Can be very difficult with disasters.

2. Social Value

- “The first and foremost obligation in acute disaster situations is to respond to the needs of those affected” (CIOMS, Guideline 20 Commentary).
- Responsible use of finite resources
- Starts with engagement with the local population.
- Harms are not justified if there is no social or scientific benefit.

3. Scientific Validity

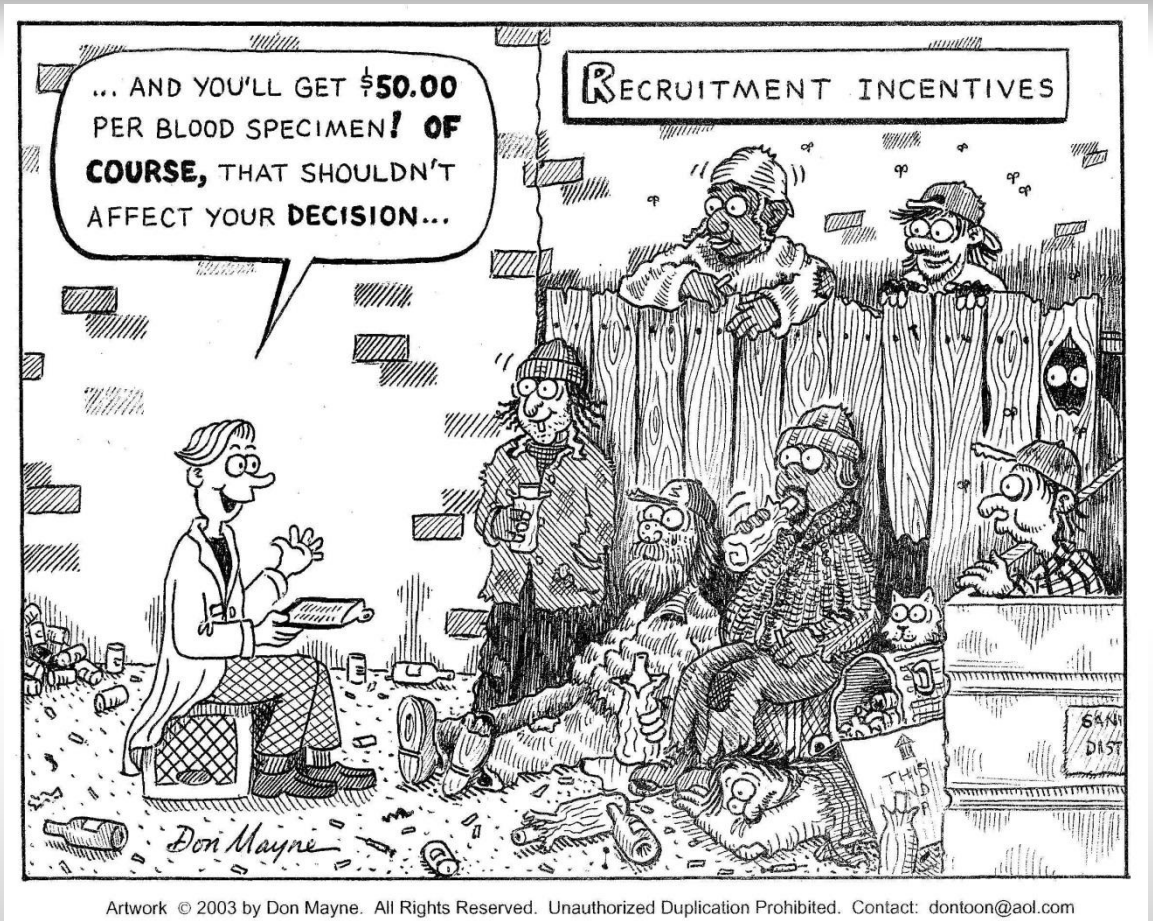
- Is the study design appropriate to the research question?
- "Qualitative research is not intrinsically more ethical or of better quality; an interview can be as unethical and poorly conceived as a bad questionnaire" (p. 315).
  - Mackensie et al. *Journal of Refugee Studies* 2007;20(2):299-319.
- Is the study feasible given the disaster situation?
- Is sufficient funding available for all phases, including dissemination?
- Researcher training and support.
- "However, as is often the case in research, many of the ethical dilemmas and challenges were unexpected and faced only once the fieldwork had begun" (pp. 313).
  - Molyneux et al. *Journal of International Development* 2009;21(2):309-326. Researcher training and support.
- Post-Research Ethics Analysis (http://globalhme.org/projects/ethics/prea/)

4. Fair Subject Selection

- Participants should be chosen because of the aims of the research and its potential outcomes, not because of privilege, access, vulnerability, convenience, etc.
- Does the study need to be done in a disaster?
- Systematic review of disaster research ethics guidelines: vulnerability one of two core themes
  - Mezinska et al. *BMC Medical Ethics* 2016:17(1):1-11.
- Are all appropriates groups included?
- Researchers “come in and just talk to the leaders and their wives—they never hear what it is really like in the camps”…; “We get no justice from the leaders, but they are the ones that UNHCR listen to” (p. 304).
  - Mackensie et al. *Journal of Refugee Studies* 2007;20(2):299-319.

5. Favorable Risk-benefit Ratio

- Risks relate to:
  - participant group
  - research methods (note psychosocial risks with qualitative research), and
  - research topic (especially social science topics).
  - AND researchers
- "If the research is determined to be of *no* benefit to the local population, then it should not be carried out" (p. s221).
  - Allden et al. *Prehospital and Disaster Medicine* 2009;24(Suppl 2): s217-s227.
- Principle of reciprocity and benefit sharing.
- Sets up other ethical challenges – e.g. providing direct benefits to participants and not the rest of the community.



- Humanitarian misconception: how will researchers reduce the risk of participants thinking that research participation is required to receive humanitarian aid?

6. Independent Review

- Second core theme in systematic review of disaster research ethics guidelines:
  - Mezinska et al. *BMC Medical Ethics* 2016:17(1):1-11.
- Researchers often have real and perceived conflicts of interests.
  - Humanitarian aid worker or researcher?
  - Duty to sending agency or survivors?
  - Association with military, political, commercial, religious goals.
- Slower review versus urgent window of research 'opportunity.'
- "Health officials and research ethics committees should develop procedures to ensure appropriate, expedient and flexible mechanisms and procedures for ethical review and oversight" (CIOMS, Guideline 20).

7. Informed Consent

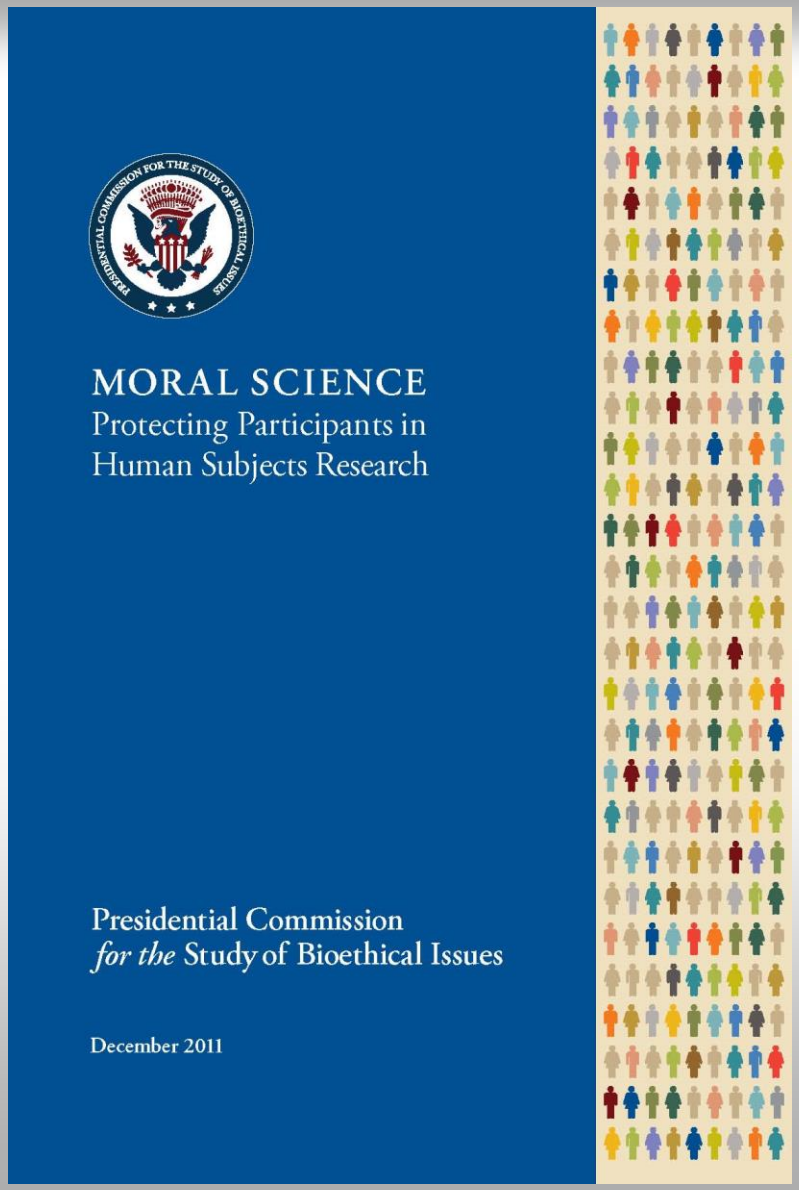
- "Ensure that … the individual informed consent of participants is obtained even in a situation of duress, unless the conditions for a waiver of informed consent are met" (CIOMS, Guideline 20).
- Huge challenge: "When I go into a horrendous camp situation as a white researcher, the people are so desperate for any form of assistance they would agree to anything just on the off-chance that I might be able to assist. It makes asking for permission to interview them or take photographs a farce" (p. 234).
  - Pittaway et al. *Journal of Human Rights Practice* 2010;2(2):229-251.

8. Respect for Participants and Communities

- Privacy and confidentiality must be protected.
- Participants have claimed researchers “stole our stories” (Pittaway et al., 2010).
- Requires careful engagement, e.g. Participant Action Research.
- “There is a conventional wisdom that ‘women do not talk about sexual abuse’. However, in camps and urban settings in five countries the researchers have found that by using this methodology, once trust is established and they have been involved in negotiating the process, the women are desperate to tell their stories and to share their experience’ (Mackensie et al., 2007: 314).

Beyond Codes and Guidelines

- Codes and guidelines can undercut the "sense of personal accountability and, hence, of the importance of personal integrity"
  - Payne et al., *Sociology and Social Research*. London: Routledge; 1981: p. 249
- While informed consent is important, the most reliable safeguard to ethical research involving humans is:
- "the presence of an intelligent, informed, conscientious, compassionate, responsible investigator."
  - Beecher HK. Ethics and clinical research. *New England Journal of Medicine* 1966;274:1354-1360



- "the virtuous researcher"
  - 'a focus on the internal ethical motivation of individual investigators, not only the rules and regulations that externally motivate investigators toward compliance' (p. 32)

https://bioethicsarchive.georgetown.edu/pcsbi/node/558.html

- Researchers and research teams need to develop the skills to:
  - identify ethical issues,
  - reflect on ethical issues,
  - reach ethical decisions that can be defended.
- AND, become virtuous researchers with the highest standards of personal and research integrity.
- Training and assessment is challenging.
- When researchers are tempted in some less than ethical direction, all they may have is their conscience and their virtues.
  - O'Mathúna DP. "The dual imperative in disaster research ethics", in the *SAGE Handbook of Qualitative Research Ethics*, eds. Ron Iphofen and Martin Tolich (in press).

Further resources

- O'Mathúna DP. Research ethics in the context of humanitarian emergencies. *Journal of Evidence-Based Medicine* 2015;8(1):31-5.
- O'Mathúna DP. Conducting research in the aftermath of disasters: ethical considerations. *Journal of Evidence-Based Medicine* 2010;3(2):65-75.
- O'Mathúna DP, Gordijn B, and Clarke, M. *Disaster Bioethics: Normative Issues when Nothing is Normal* (Springer, 2014).
- http://DisasterBioethics.eu
- https://humanitarianhealthethics.net
- https://BioethicsIreland.ie/disasters

Thank You!